

A CONCURRENT RESOLUTION decrying the lack of services and specialized services for medically fragile young adults with intellectual and developmental disabilities and directing the establishment of the Task Force on Subacute Care for Medically Fragile Adults.

WHEREAS, at the age of 21, the life expectancy of a medically fragile young adult is two to three years because of the substandard care available to this population in our Commonwealth; and

WHEREAS, the care available to individuals younger than 21 who are medically fragile and who may require daily skilled nursing intervention such as ventilators, dialysis machines, feeding tubes, or continuous oxygen is adequate and allows many individuals to thrive prior to age 21; and

WHEREAS, when individuals age out of these specialized services on their 21st birthday, the availability of adequate care disappears; and

WHEREAS, because of lack of funds on the federal and state levels the nurse-to-patient ratio drops from about one nurse for every eight patients to one nurse for every 24 patients upon aging out or otherwise losing specialized services; and

WHEREAS, most medically fragile residents are nonverbal, and their needs require anticipation by experienced staff; and

WHEREAS, many staff in adult nursing homes are not familiar with the needs of medically fragile young adults, including deep suctioning, feeding tubes, and providing medications through feeding tubes; and

WHEREAS, young adults have different socialization needs than what is available in adult nursing homes; and

WHEREAS, medication timing and frequency changes as these individuals grow older and their care situations changes; and

WHEREAS, tub bathing for the medically fragile often is reduced from once per day in most care settings prior to age 21 to twice per week or fewer in a nursing home;

and

WHEREAS, access to community age-appropriate activities is greatly reduced for many residents; and

WHEREAS, access to educational programs, peer modeling, and socialization is greatly reduced for these citizens after age 21; and

WHEREAS, access to critical assistive technology such as standers, gait trainers, and other necessary equipment is compromised; and

WHEREAS, private rooms are not available for this population, and they may share rooms with individuals prone to behavior issues, which is particularly concerning for this nonverbal population; and

WHEREAS, family members cannot spend the night to visit their family member at many adult nursing facilities; and

WHEREAS, there is little availability of bus transportation or other public transportation to many nursing facilities, which further impacts the ability of families to visit residents; and

WHEREAS, properly equipped ambulances for transportation of a patient from a nursing facility to a hospital are often not available; and

WHEREAS, targeted therapies for this population are extremely limited because many nursing facilities are focused on the aged; and

WHEREAS, subacute care is very limited in the Commonwealth, with one of the most effective treatment facilities having an eight-year or longer waiting list; and

WHEREAS, subacute care could be a health care growth area in the Commonwealth as additional therapies are covered and developed; and

WHEREAS, many of these patients have thrived and survived thanks to medical advances and outstanding care available in facilities that serve medically fragile children; and

WHEREAS, the Commonwealth has the opportunity to expand subacute care and

empower these individuals to continue to thrive;

NOW, THEREFORE,

***Be it resolved by the House of Representatives of the General Assembly of the Commonwealth of Kentucky, the Senate concurring therein:***

□Section 1. The Legislative Research Commission is directed to establish the Task Force on Subacute Care for Medically Fragile Adults to develop a strategy and funding mechanism to provide medically fragile adults with intellectual and developmental disabilities with care that is equivalent and synergistic to the care received by children with diagnoses of intellectual and developmental disabilities with medical complexity. The task force shall invite representatives of agencies, hospitals, providers, businesses, civic organizations, and others who may provide information and resources in developing and implementing a strategy, legislation, research, and funding mechanism for better serving the underserved population of medically fragile adults with intellectual and developmental disabilities.

□Section 2. (1)The task force of the Legislative Research Commission shall be composed of the following members with final membership of the task force being subject to the consideration and approval of the Legislative Research Commission:

- (a) The chair of the Senate Health and Welfare Committee;
- (b) The chair of the House Health and Welfare Committee;
- (c) The chair of the Senate Licensing, Occupations and Administrative Regulations Committee;
- (d) The chair of the House Licensing and Occupations Committee;
- (e) Three members of the Senate, two to be appointed by the President of the Senate, and one to be appointed by the Minority Floor Leader of the Senate; and
- (f) Three members of the House of Representatives, two to be appointed by the Speaker of the House, and one to be appointed by the Minority Floor Leader of the House.

(2) The President of the Senate and the Speaker of the House shall each appoint one co-chair of the task force from among the members of the task force.

□Section 3. The task force shall report its findings to the Legislative Research Commission for referral to the appropriate committee or committees no later than December 1, 2017

□Section 4. Provisions of Sections 1 to 3 of this Concurrent Resolution to the contrary notwithstanding, the Legislative Research Commission shall have the authority to alternatively assign the issues identified in this Concurrent Resolution to an interim joint committee or subcommittee thereof, and to designate a study completion date.